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## Living with Multiple Sclerosis: A Look into the Life of a Mother with MS

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# Living with Multiple Sclerosis

*A Look into the Life of a Mother with MS*



Written by Allison Murphy

Illustrated by Caroline Oehlerich

**T**he initial diagnosis was a long time coming (6 years of complaining to my doctors), because my symptoms are mild comparable to some patients and was attributed to being “all in my head” or a response to stress. It wasn’t until I had trouble walking that I saw a neurologist and had an MRI. I have mild Multiple Sclerosis.”

Think of the neurons in your nervous system as a complex circuit of interconnecting wires. The signals that these wires transmit and send are responsible for every aspect of your life: thinking, feeling, moving. Like any other part of your body, these wires are normally protected by your immune system. Multiple sclerosis (MS) manifests when the system meant to protect the nerves ends up destroying them instead. MS is a progressive, degenerative, autoimmune disease that affects around 2.3 million people worldwide, including Elizabeth Murphy, who is quoted above. In an autoimmune disease, the body’s immune system attacks the very body it’s meant to defend. During multiple sclerosis, the immune system creates inflammation that damages the central nervous system.

If neurons are wires, then you can compare myelin to the rubber insulation that covers them. It is a fatty substance manufactured by glial cells, which are just as or even more numerous as the signal-conducting neurons in your brain and body. This substance coats the axons of neurons, which helps make the electrical impulses traveling down those axons conduct to its neighbors more quickly and smoothly. Without it, the conduction slows down and communication is damaged or signals are

lost. MS often damages the myelin coating, causing problems with signal transmission. It can also cause damage to the glial cells that create the myelin as well as the underlying neuron the myelin is trying to protect. The results of this damage can often be seen as lesions in the brain, which are detectable when the brain is imaged during an MRI.

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The disease is progressive, and the course is different for every patient. Most patients have what is referred to as a “relapsing-remitting” course, which consists of “exacerbations” of heightened symptoms followed by periods of decreased disease activity. Others have a “progressive” course, consisting of continually worsening symptoms with a more sudden onset. In some rarer cases, there could be a combination of the two or a switch from one course to the other. It is sometimes referred to as a “snowflake disease” — no two people have the same history or severity of symptoms.

*“If people find out about my MS it becomes an identifier — ‘You know her, she’s the one with MS.’ People don’t know that I have annoying*

*pain that doesn't go away. It wakes me up, it is worse at times, and I can't take anything for it. I have tried medications for nerve pain but they have proven ineffective. Some people think that it can't be that bad because I don't complain or have obvious symptoms; I am not in a wheelchair. I am truly thankful that it isn't "that bad," but it would give my MS symptoms more credibility when I am having a bad day and not showing it."*

The damage for most patients occurs during relapses and can be temporary or permanent. There's no way to predict what the target of these attacks will be — what "wires" will be damaged — but there are some symptoms that are common in MS. The optic or auditory nerves, which help with vision and hearing, respectively, are common targets. Results can range from temporary sensory deficits to total blindness, which may or may not be permanent. Problems with muscle control, spasticity, and coordination can lead to changes in motor function. About half of patients will experience decline in memory and cognition. Clinical depression, whether as a result of damage to the brain or of other debilitating symptoms, is common as well.

Every patient's experience is different, however, and the effects of MS are varied and often unpredictable. For Elizabeth, many symptoms are sensory. She has peripheral neuropathy in her left leg, which causes numbness or pain that she cannot control or ease. Her right leg experiences "foot drop," a loss of muscle function when she walks. She occasionally experiences trigeminal neuralgia, leading to numbness and pain in nerves along her jaw. A phenomenon called the MS "hug" leads to a constricting sensation around her torso. She has tinnitus, a high-pitched ringing noise in her ears that many may experience after listening to a loud concert, but for her is incessant. Other symptoms include nausea, vertigo, and fatigue combined with an inability to sleep well.

Elizabeth recognizes that her case is comparatively mild; it is not uncommon for those with MS to lose motor function and use walking aids or a wheelchair. She is a full-time clinician in an intensive care unit, and without talking to her it would be nearly impossible to guess her condition. While MS can cause relapses leading to hospitalization, it can also present itself as an "invisible disease." This can be frustrating for many people with MS, who experience debilitating symptoms that aren't always apparent. Even medical professionals that Elizabeth knows well will seemingly disbelieve her diagnosis, saying that she looks "too well," pointing out that she is not one of the sufferers in a wheelchair, thinking that because she does not complain, there is nothing wrong. Although the course of the disease can vary, it would be misleading to say there is a "good" MS.

*Elizabeth is seated with a syringe in her right hand. Staring at her bared thigh, she inhales, then plunges the needle into her muscle and quickly injects its contents. Before heading to bed, she swallows two ibuprofen to prevent the flu-like side effects to come. This has been a weekly routine for years.*

Inside Elizabeth's needle is beta interferon, a protein that cells in the body and immune system use to signal to each other. It is also a substance that is released during illness, which means that Elizabeth experiences side effects such as fever, fatigue, and muscle aches. Taking it helps balance the overactive immune system, reducing inflammation that can cause neuronal damage. Many MS medications function in this way, intended to stop the immune system from causing further damaging attacks. There is no cure for MS, and so most treatments aim to alter the course of the disease, prevent relapses, and lessen damage over time. Other treatments work during a relapse period and involve an I.V. infusion of corticosteroids, which regulate the function of the immune system to reduce the length and damage of the relapse. Although these medications can limit damage and increase quality of life over a prolonged period, there is no cure for MS.

Furthermore, a patient with progressive MS may not be able to use these treatment options. Those who can use them sometimes find that the side effects, whether from the drug itself or from the complications of constant injections, are too severe and must try several different treatments. Other prescriptions given for MS intend to manage, rather than prevent, symptoms. Medications can help alleviate muscle spasticity, bladder problems, pain, emotional changes, or depression. In cases where symptoms make it difficult to walk, physical therapy can be useful. Stem cell therapy is one of the newest lines of research, hoping to use new, undifferentiated cells to repair a broken immune system and the damage it causes.

*"As an ICU nurse I see patients with end stage MS. I see all of their losses in function and cognition...MS takes everything from its sufferers. Slowly, with teased moments of wellness, and then it comes back worse."*

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The prognosis for MS varies depending on an innumerable number of factors, including the age of onset, medications taken, and the course of the disease (progressive cases tend to have a poorer prognosis than relapsing-remitting). A majority of patients are able to walk, possibly with some assistance, throughout their lives. Life expectancy is, on average, about 30 years from onset or 5-10 years less than someone without the disease, but some cases progress rapidly and can quickly become fatal. For many long-term sufferers, complications from the disease can be a cause of death. However, with expanding research, a number of treatment options, and better care, the length and quality of life with an MS diagnosis has improved.

*"I work to make sure that I work out and run to keep myself healthy," she states. Her Facebook timeline is littered with "check-ins" to a local running trail. She regularly logs 6-10 miles during these runs, occasionally training for a half marathon. Between runs, she pulls out an Insanity or P90X workout DVD from her growing collection.*

Each MS story is different, and the one I chose to illustrate this disease — that of my own mom is an atypical one. Despite the fatigue, the dysfunction in her legs, and the side effects of her medications, she regularly performs physical feats that people without MS would struggle to do. The determination and athletic ability in the face of these challenges is incredible, and her above-average cardiovascular fitness and muscle strength likely helps lessen the effects of her diagnosis.

Not every experience looks like my mom's. While some of her challenges include making it to the finish line or the end of a set of jump squats, others may struggle with visual impairment or taking steps across the room. Those with a sudden onset of MS symptoms do not get the chance to build up their physical fitness before being confined to a wheelchair. But many may share similar obstacles: getting out of bed in the morning, managing a pain that can never go away, and experiencing chronic symptoms that are felt daily but go unseen by others. MS is progressive, and those diagnosed with it often live in uncertainty of what damage it will cause next.

*"I do have a better appreciation of what I have, and it has given me a different perspective about what things are important, what I need to be worried about, and what moments I should treasure. I am thankful my MS is mild." ●*